
Patient advocates vital to stem cell research progress

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Nature Medicine carried a piece Friday by CIRM governing board member Jeff Sheehy, writing about the importance of having a patient advocate voice in biomedical research. Sheehy, who is living with HIV, is a long-time advocate for HIV/AIDS research. He has been on the CIRM board since the beginning in November 2004, and is a vocal participant in CIRM working groups including the group that makes research funding recommendations to the full board (the Grants Working Group), for which he is vice-chair.

Sheehy writes:

“ The presence of vocal, engaged patient advocates has added an indispensable dimension to the proceedings. In measuring research quality, advocates tend to focus on a project's ability to benefit people-not just drive scientific curiosity-which keeps even basic biomedical research grounded in its ability to produce concrete health benefits.

CIRM's governing board includes 12 patient advocates representing HIV/AIDS, MS, diabetes (type 1 and type 2), heart disease, spinal cord injury, cancer, Alzheimer's disease, Parkinson's disease and autism. Sheehy goes on to say:

“ ... CIRM is made up of patient advocates from a wide spectrum of diseases and conditions who work together to advance therapies across the board. And contrary to critics' assertions, these advocates have not narrowly focused on their own diseases, but have uniformly advocated for the best approaches for moving basic research towards the clinic. They support each other.

Patient advocates serve a powerful role even if they aren't directly involved in funding decisions. Don Reed has been a vocal supporter of stem cell research since his son Roman Reed suffered a spinal cord injury. He is sponsor of the Roman Reed Spinal Cord Injury Research Act that funds spinal cord research in California, founder and co-chair of Californians for Cures and blogger on his own site www.stemcellbattles.com and for the Huffington Post.

In a recent Huffington Post blog entry about the World Stem Cell Summit he wrote about the importance of patient advocates staying involved in stem cell research at a political level, in order to maintain the U.S. leadership in stem cell research:

“ But unless we in the patient advocacy community can encourage Congress to pass a stem cell research protection act the dream will have been stolen.

CIRM came about in part because of the passion and support of patient advocates like Sheehy and Reed, and they continue to be a crucial part of the success of CIRM and of the progress made in stem cell research.

Here's Sheehy advocating for a stem cell therapy for HIV/AIDS. CIRM has funded two disease teams (City of Hope and UCLA) focusing on developing therapies for the disease.

Tags: Disease Team, University of California Los Angeles, city of hope

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